# People Leading Accessible Networks of Support (PLANS) Family Support 360 Statewide Workgroup June 22<sup>nd</sup>, 2006 Redfield, SD South Dakota Developmental Center

#### CALL TO ORDER

Travis called the meeting to order at 8:30 a.m. on June 22, 2006.



Members present were: Kristen Blaschke, Mike Broderick, Brenda Smith, Anne Rieck-McFarland, Wanda Seiler, Tim Neyhart, Beth Hosek, Ted Williams, Linda Daughters, Danny Spotted Eagle, Travis Arneson, Dawn Kellogg and Shirley Stirling

Others present were: Arlene Poncelet, Yvonne Reynolds, Patrice Wilson, Gloria Pearson, Colleen Ronning, Edith Arneson, Randy Meendering, John Roether, Brooke Lusk, Tarra Stoeser, Dixon (Danny's personal attendant), Deb Petersen, Jean-Claire Hamblin, Kristin Kiner, and Teri Sass

#### **Announcements - Ted**

Ted made some general announcements and welcomed everyone to the South Dakota Developmental Center. Staff will be giving us a group tour later this morning.

#### **Announcements - Travis**

Linda Daughters has taken a new job with the Mental Health Center in Winner but she has agreed to stay on with the PLANS workgroup. We would like to welcome her back onto this group under that new title.



#### Announcements – Brooke

- Brooke spoke about the handouts. The fact sheets for each area will be updated by the PLANS Coordinators and sent before each meeting.
- The Coordinator Profiles gives a description of each Family Support and PLANS Coordinator. This tool is to help families make a decision about which Coordinator they would like to work with. A video or DVD is a possibility for the future.

- The Fall conference will be held in Spearfish in October and it will be a regional conference. This should be very beneficial for South Dakota in regard to the caliber of speakers.
- Dave Hammis will be here the 1<sup>st</sup> week of August for four days. There are three different registration forms that you have. He will be going through the discovery process with us, how to write a business plan, and work incentives to use for sel-employment. There will be an advanced training on Aug 2<sup>nd</sup> & 3<sup>rd</sup> on Self-Employment. The Benefits Specialists, VR Counselors, and support staff will be attending and learning how to support people who choose self-employment. Get the registration forms in as soon as possible because space is limited.
- Hoby Abernathy is no longer going to be a part of the PLANS Project.
   Betsy Valnes will be the new Project Coordinator.
- Project staff submitted the continuation application and the third year of the grant will start September 30<sup>th</sup>, 2006. Later today we will be discussing activities for the priority areas you identified at the last meeting.

## Core Stakeholders Report – Dawn Kellogg and Brenda Smith

- The Core Stakeholders met yesterday.
- The first topic was a discussion about independent case management options in Arizona, Minnesota, Oregon, and Maryland.
- John Roether spoke about the change in Arizona to provide independent case management.
- Started with three pilot projects in about 1999. The support coordinators were picked by the individuals. Arizona also has support coordinators hired by the Division. The implementation was statewide in 2003.
- Tom Schienost spoke about case management in Minnesota. In Minnesota, the county receives the money and distributes it. Also, in Minnesota, you are "assigned" to one case manager and that person "moves" with you no matter where you go in the state.
- Jean Tuller spoke about Oregon and Maryland. Oregon had an independent entity that had independent case managers. They had access to personal support brokers. In Maryland, they used an RFP for case management.
- Brenda mentioned that these were all good examples of case management. The group talked about doing focus groups across the state and a survey to collect information from a good cross section.
- One focus group may be with individuals and another providers so that everyone feels comfortable speaking and asking questions.
- Jean spoke about Good to Great (G2G) and how agencies can utilize
  these services. We discussed whether it would be a competitive process
  or not and decided it would be. We also decided that agencies who were
  part of the process one year, would not be eligible the next.

- A subcommittee comprised of members from the Core Stakeholders and the DD council will review the applications and determine which agencies will be involved.
- Jean is putting together an application process to facilitate this.

# **DD Council grant – Arlene Poncelet**

- The DD Council granted funding for this project with match funds provided by the Division.
- The Council is excited about this opportunity to work on systems change.

## South Dakota Developmental Center (SDDC) history – Ted Williams

- Ted showed a video on the background of the SDDC and the alumni. The video celebrated 100 years for SDDC. SDDC began in 1902. The video is four years old and they have made many changes since it was created.
- One thing they are attempting to do is to not make it so comfortable for people so that they can and will leave. Currently serving 163 people.
- They've also learned that people with challenging behaviors don't do well when they don't have their own space, so they do what they can to accommodate this.
- Staff came back from the community development conference and didn't
  feel so good about themselves anymore. Six or seven people went. We
  have an image out there of being an institution. We came up with an
  initiative to close the institutes and we are trying to get rid of those things
  that make us look like an institute. We need to look at person-centered
  language. Our little group grew from six people to thirty people. Some of
  the people live here and we welcome them.
- We talked about workshops as opposed to people saying "I am going to work", which sounds less institutionalized.
- What do we call people who live here: patients, residents, clients, individuals, and etcetera. We are working very hard not to label – trying to use their names.
- If you see/hear something during tour that sounds institutionalized, please let Ted know.
- The small group goes out and talks to the others and it is interesting to see that change occur.
- Ted introduced the program directors and the programs they manager.
   Program 1 is the transition area. People do better if we move them
   gradually into a less structured system. Program 2 is the Turtle Creek
   Youth Program, which started in 1998 and contains 40 beds. The
   youngest is 11 and the oldest is 21. Program 3 is the cottage area, which
   is the mixed area.

The PLANS group split into three groups and then took a tour of the South Dakota Developmental Center and the campus.

# Individual Budgets – Iowa Meeting – Brenda Smith, Kristin Kiner and Teri Sass – Refer to pamphlet.

- Kristin and Teri attended a meeting in Iowa.
- Worked with pamphlet from the Center for Self-Determination:
   Guaranteeing the Promise of Freedom: Creative Individual Budgeting
- www.self-determination.com

#### Kristin

- It really opened up their eyes to what there is to come.
- They saw what could be.
- We need to stay focused on the person and it will work out in the end.
- We need to let them have the freedom and flexibility in their budget, it is not what we want, it is what THEY want.
- Talked a lot about public funding.
- In lowa, the people actually had their own federal Identification number.
- There are tons of options out there.

## Teri

- We came away feeling very fulfilled. Feels very good about what SD does with PLANS.
- Main theme: It's all about the person. It is driven by the person.
- Unique thing about this tool is that you really focus on the person.
- Hiring job supports on the job.
- The whole process is based on the person.
- Empowering.
- How do you create natural supports?
- Individualized support broker is the equivalent of the PLANS coordinator.
- A personal agent may just be for one person.
- Ran payments of supports thru credit unions.
- Credit union charges a flat fee to do that.
- Person centered, driven and built around the person. That is what we are trying to do in PLANS now.

John: In Iowa, where they able to hire family members.

Brenda: I don't know if anybody at that time was a family member.

#### Brenda

- Very eye-opening.
- Sees the possibilities out there.
- This makes you think about what it really costs to live for a year.
- Section 2 Community and relationships it takes money to be part of the community. Going to movies, companionship, giving gifts and cards,



going to rec center, church, cd's and music, traveling to and from volunteer jobs,

- Section 3 what is he getting from his job.
- Transportation is a big part of the budget.
- What kinds of support are needed and what do they cost?
- Try to be as flexible as possible.

Mike: At what point do you expect get this funding?

Kristin: I don't know. I am doing everything I can as a PLANS coordinator to do

what I can with my funds.

Brenda: This is certainly a tool that works.

Lunch

## **Housing – Tim Neyhart**

- Arlene and Tim are working on housing manual
- Tim's office has the funds to print and distribute the publications and they hope to do so in the near future.
- They continue to look for individuals with housing needs and find ways to help them if possible.
- The state has funding for accessible homes now it is just a question of transportation accessibility.

# Housing - Rural Development - Dave Franssens & Shannon Kleinsasser - refer to handouts.

- USDA Rural Development offers loan and grant programs and technical assistance and services to rural communities and individuals.
- The overall mission of USDA Rural Development is to improve the quality of life of rural South Dakotans. To accomplish this we have the responsibility of coordinating specific federal assistance programs in rural areas of our great state.
- www.rurdev.usda.gov/sd
- http://www.rurdev.usda.gov/sd/rural housing programs.htm

#### Questions:

Brooke: Other than income, do homes have to be in certain communities?

Shannon: We are in smaller communities. We cannot do Rapid City, Sioux Falls and Aberdeen (Aberdeen is temporary).

# Housing – SD Housing Authority - Vona Johnson – refer to handouts

Deferred payment mortgage loans.

- There is no cookie cutter that will work to get everyone into homes.
- Need to get some real life individuals who are really interested in home ownership.
- The ideal is home ownership.
- Can we give people the opportunities?
- They are contracting with the state to list all rental properties.
- http://www.sdhousingsearch.com/
- http://www.sdhda.org/

#### Questions:

Randy:

Vona: We have actually financed several properties, one in Miller, one in Huron.

8 unit complex with commonaries. Each individual also has their own apt.

Interested in doing more than that. Typically it takes a developer.

Randy:

Vona: Home can be used for home ownership.

Brooke: If we go to the website <a href="www.rurdev.usda.gov/sd">www.rurdev.usda.gov/sd</a> are there income

guidelines listed? Shannon: Yes

Brooke: If we need to contact someone in your office or pass along information,

how do we do that?

Shannon: There are numbers on the brochures and when you call the number

there are contacts for that at each office.

### **Transportation – Jackie Mattheis**

- ROCS Rural Office of Community Service.
- SD has 23 public transit providers in 211 communities in the state.
- Major goal is to provide transportation in every community in order to keep people in their homes for as long as they can.
- All public transportation has an accessible vehicle. The first one purchased has to be accessible.
- One office coordinates the transportation.
- You must call in advance to schedule a ride.
- http://www.sddot.com/fpa/transit/docs/TransitBrochure2006.pdf
- http://www.apta.com/links/state\_local/sd.cfm
- The Senior Center program caters to the elderly.

Linda: The ROCS in Winner is great. The problem is the hours. Does each area set their own?

Jackie: Some do. If there is a driver in that area, they may work with you. Most of them you have to give 24 hour advance notification if you need a ride.

We suggest you start with the ROCS office and see what they have to offer for hours.

Ted: Are their liability issues with that?

Jackie: Yes, in some areas we have to have extra insurance. All the drivers have to pass certain tests to be eligible.



Brooke: Are the providers keeping track of rides that get turned down? Jackie: We ask that our drivers do not turn down any rides. If you find that happening frequently, please contact our office and we will take care of it. Also, we are currently putting a program in place that will record the calls, call times, and the times picked up and dropped off.

Travis: Are you working on any individual programs in the area where you have the 24 hour call in?

Jackie: There are two areas in SD that offer 24 hour service: River City Transit in Pierre and in Mitchell.

Travis: Would there ever be a way around that and do you see that expanding to other areas?

Jackie: We have to watch what we do because of the private industries.

Dawn: What kind of training do the drivers have to take in order to handle these individuals.

Jackie: We are training our drivers and it should take a year in order to get them all trained. We call it PASS training. Also, we require them to take CPR and defensive driving training. The state pays for all the training for all the drivers in the state, as well as their transportation costs for the training.

Travis: Are there any laws or guidelines about fastening wheelchairs down? Jackie: Yes, there are laws on how the wheelchairs are to be fastened down and how tight the harnesses are supposed to be in the buses. We are providing all we can to make sure that they have a safe ride. All buses have to meet ADA requirements.

Travis: Do you know that law?

Jackie: I don't know the law specifically; I just know that all buses have to meet the ADA requirements.

Brooke: Do the independent providers set their own rates, or is it the same across the board?

Jackie: Is it usually an across the board rate that they are charged.

# Inclusive Worship – Brenda Grogan

- Works at ECCO as service coordinator.
- Encourage participants to attend one of the seven churches in Madison.
- Staff will go with them if needed but the focus should not be on the staff member, it should be the parishioner.
- You may have some people that you support that have limited social skills. They are going to need lots of initiation.
- Faith-based organizations are great social settings for people.
- Social skills have been known to improve after attending such organizations.
- Potlucks and other church activities promote inclusion.



- Have several people who are greeters at church. Talk to the pastor or priest for more information on how to become involved in church activities.
- One gentleman is an usher. Had to explain some of his idiosyncrasies to the other ushers. Now, he has been ushering every Sunday for eight years (unless he visits home.)
- Knights of Columbus are another great group for men to join.
- The downfall to some of the things is that some people who feel that some people shouldn't go to communion or do these things because they think they don't understand. We still have to educate one person at a time.
- No one can judge whether or not someone has spirituality. It is for God to know.
- Some people wanted to have a segregated divinity class for the people at ECCO. We said absolutely not – if you have a congregational class then they should be included.
- Educate, educate, educate; Involve, involve, involve.
- As time goes on, the congregation and the priest do come around.
- The more that people attend and the more involved they are, the more they are going to be missed.
- One gentleman would wave to God when he left every time. Very humbling.
- The key is to stand strong with the congregation and eventually they will come around.
- More information on inclusion can be found at the South Dakota Parent Connection. <a href="http://www.sdparent.org/">http://www.sdparent.org/</a>

#### **Teri-Worship with her participants**

- Has had some great success in the northeast area of the state.
- You have to let people know that they can be involved in church activities.
- Volunteering has become very popular in her area.
- You do have to educate people a little bit and sometimes sell the idea, but usually it all works out for the best.
- Overall, natural supports work the best.

#### Kristin- worship with her participants

- Went to the parish priest and asked him his thoughts.
- REACH Program Religious Education for All Children.
- Has someone help coordinate getting the people together.
- In the first couple of years they had a bible study and studied the commandments.
- This last year to improve more people in the church community was to involve youth groups.
- Also have a new group called Partners in Faith and it is for adults.
- The youth groups coordinate activities with the church.
- Anyone is welcome to participate in these activities.
- As more people get involved with the church, more interest is generated.

John: Was there any work done for inclusive worship or anything being done across the state to promote or improve Native American worship?

Teri: Not in my area, but in the Rockhold area they are very into it. Of course if I had people interested I would check into it for them.

Kristin: I haven't either and I haven't had any requests for it.

Danny: I haven't heard of anything like that except for the one I attended on the reservation. I haven't heard of anything like that around here.

Travis: I have a question for Jackie. You mentioned inviting someone to your church as a natural resource and you also suggest the direct support professional (DSP) should never be the main focus. If I was a direct support professional and invited someone to my church it would be unnatural to make the person with the disability the focus.

Brenda: I was referring to an example where the DSP goes with the participant and the participant is ignored. The DSP should try and stay out of the focus of attention and allow the participant to talk, etc.

Travis:

John: As I look across the board, I don't see the Native Americans being represented.

Danny: What do you mean?

John: I was at the meeting yesterday and now today and I don't feel the Native Americans are properly represented.

Danny: That is because the tribe has never heard of this group before.

John: I believe that the Division has the responsibility to ensure that we are being properly represented and included.

Mike: I would like to follow up on your comments. You don't consider you and Danny as representing the Native American population?

John: What I am saying is I don't see representation in these boards as being enough.

Travis: I would like to make a comment please. We have been looking at that issue ourselves. We are now trying to recruit one more individual with a disability who is Native American. Hopefully that will help out with a couple of our downfalls.

Danny: Where have you been looking?

Travis: We have been looking across the state.

Danny: You could call around to the tribal offices and then maybe they can find someone local.

Travis: Brooke and I gave Wanda a list and I think we will be seeing someone at the next meeting.

Danny: Maybe you could email that to me and I could look for someone.

John: I guess for me it is more about exposure. I see for myself as a Native American what is going on in the Division and I would like to see more tribal representation. Native Americans take things back to their own tribe and I don't see that happening here. They don't know that there is something out there.

Mike: Are you suggesting educating each tribal government?

John: Not necessarily, I think that one person would be enough. I think it needs to be diverse tribal representation.

Danny: Has anybody talked to the tribes about it?

Brooke: We have talked to some about tribal segregation and things like that.

Danny: Somebody should tell them.

Travis: Are there anymore comments?

Wanda: The other thing I would add is that we do have tribal representation here and in our staff. Another good point is that we can't pick just a few tribes or we will be in hot water with the other tribes. I just don't want to minimize the representation that we do have on our boards and in the division.

John: I agree with what you are saying. I just would like to see more representation of the tribes. It's not about disabilities, it's about tribal growth.

Travis: I would like to thank the speakers for coming and everyone for their input.

#### Afternoon Break

Travis: The last three items that we talked about we now need to discuss how we want to implement them and what we want to do for this group.

Brooke: Remember back in March, you as a group identified priority areas for the grant. These are some of those items.

Travis: Transportation has always been a big issue and I know someone has something to say about that.

Ted: Isn't one issue the hours?

Danny: Yes.

Mike: When it comes to hours, isn't money a big issue? I know it is in our town and we have ROCS. We put together the ROCS system primarily for our seniors and now we are servicing more students.

Danny: Like on Saturdays we have to find our way home if we want to go to activities. The service I use would cost \$32 to \$35.

Anne: I think part of it is the timing. It can be an hour to 45 minutes from appointment to appointment. They arrive early or you have to wait until they can come and pick you up.

# **Action Steps (Brooke on flip chart)**

- Housing info on website.
- Motivation to downsize group homes (options turn to something else).
- Control of living environment.

# Inclusive Worship

- Accessibility.
- Parent Connection document (reprinting) (review).
- Talk to Ministerial Associates (sensitivity, education, info).
- Transportation.
- Example of using funds for transportation (purchase vehicles, etc).
- Red top van in D.C. as example.

Priorities at different times of day and people and rates.

### Housing

- People who own their homes talking to other people.
- Booklet (include stories and pictures) (different example) (distribution).
- DVD.
- Loan program info available.
- Tim's got money.
- HERO program in accessible format.

#### **Activities for Priority Areas**

- 1) Housing.
- 2) Transportation.
  - Hours and costs and timing (pick up and drop off not on route).
  - Safety.
  - Are these expectations the same for everyone?
  - Duplication of resources (cooperation and autonomy giving up).
  - Public vs. Private (24 hour timeline).



### **Transportation**

Travis: I asked Jackie about that 24 hour window and she said they have to have that to protect the private companies. I am wondering what the impact on the economy and the system to let private companies collect the same kind of money. Private vs. public. Hopefully eliminate that 24 hour timeline.

Brenda: As we look at the future, is it possible to purchase a vehicle or hire a driver?

Travis: Ted asked for a good example. I believe Washington has one. It's still a wait and the vans and buses are universal they just keep going no matter what the ability is. And they are low profile.

Randy: I know the issue in Huron is that during school pick up times it is impossible to get a lift because that is their priority. I think it is a financial issue.

Dixon: I am not part of this group, but I would like to add something. Last Saturday, there was a terrible rainstorm. The transit was dropping off the individual's at their homes. Isn't there somewhere they should take the individual's during a storm warning rather than dropping them off at their apartment?

Travis: I know I personally would want to keep about my day, rain or shine. Most everybody else doesn't stop their life over rain. I was at my bank four blocks and had to call Edith for a ride.

Randy: It would be interesting to know if other people who use transits have the same expectations and the same window as Danny mentioned.

Danny: Would it be proper to talk to the mayor?

Brooke: It would probably be more beneficial to talk to the providers and get their input.



#### Housing

Shirley: A young gentleman in Miller bought his own home and I suggested to him that he should do a presentation on how he went about advocating for it. He needs to gain confidence and experience. Perhaps he could come and practice on our group?

Anne: Why couldn't we do something that shows what people like Danny are doing? His apartment was modified to make it completely accessible.

Tim: Actually it is going to be in our manual.

Danny: Why can't we make a DVD and give it to each agency? And then if they have questions they can email one of us who shares their stories? Tim: There are other people who have other stories. Maybe we could contact them. I think we should put housing on the website – at least Vona's information.

Brooke: Betsy Valnes will be working with Tarra and Beth Henricksen on updating the website with the ideas from the last meeting. I will make sure and pass along your input.

Travis: I don't want to hamper this discussion, but we have one more point to discuss. If you have anymore suggestions on housing please call or email Brooke at 605-224-5336 or <a href="mailto:blusk@tie.net">blusk@tie.net</a>.

# **Inclusive Worship**

Travis: I think that accessibility is a big issue. Some of them have been around for quite a while - they have the right heart but the wrong building.

Arlene: The Council developed a training curriculum about five years ago called "All One Under God" and sent it out to all the churches and places of worship. We could possibly get more printed. I have some federal money that might need a little match to go with it.

Danny: Where would we get them printed?

Arlene: I don't know – we would have to check out printing companies.

Travis: What about CD or DVD?

Arlene: It is possible. And we could possibly put it on the website. It's been a while, so I would have to re-read it to make sure that it is in "People First" language.





Cindv

- She services the north-central areas of South Dakota.
- For parents, we have Parent Briefs.
- For students, we have a self-determination brochure.
- Also included in the Tacklebox we have information on Catch the Wave.

- In the handbook, we have Quickbooks for assessments. Gives various types of assessments.
- Transition website: <u>www.tslp.org</u>
- We also provide trainings for the Tacklebox and the other items mentioned.
- For students we have the Youth Leadership Forum. Teri's son was a delegate for that and she said he is still talking about it.
- The Youth Leadership Forum is a career and leadership training program for high school juniors and seniors to learn more about self-advocacy skills, disability awareness, etc.
- Catch The Wave is a transition sponsored event. Catch the Wave is a day of university orientation for high school sophomores with disabilities who are considering post-secondary education.
- Dare To Dream is another transition sponsored event.
- Any suggestions can be sent to the liaisons or Brooke.
- There is a lot of information available, but it is getting it out there is key.
- For more information about any of these items or transition related questions email Cindy at <u>cindy.kirschman@state.sd.us</u>.

#### Wanda

- Daryl has agreed to be our guinea pig.
- VOA Turning Point is the next agency up for accreditation.

#### **CMS Waiver Review**

- Went well, minimal recommendations.
- Ability of ATC's to bill Medicaid themselves instead of thru fiscal agent.
- People providing services as domestic employees.
- There have been more and more emerging lawsuits. They are employees and not independent contractors. The IRS has issued clarification in this manner.
- We are scrambling to address this issue. Working with Oregon company, Thin Logic.
- We have elected to resolve this issue with a model.
- Planning to have CES folks here at next meeting to demo software. Hope to be on verge of implementation in Sept when we meet again.
- Found no state is really happy with their fiscal mediary system.



There were things that off the agenda

Travis: some were left this morning.



- As for the definitions: Brooke will email the group a final copy so everyone is on the same page.
- The next item is the name change. I'm leaving it up to you how to handle it. It has to be handled soon but it is almost 5.

Brooke: The Family Support council has discussed it.

Travis: Do you want an update from Family Support or what?

Anne: Is there a recommendation?

Wanda: We suggested Family Support 360 Coordinators, but not everyone on

this group is comfortable with this.

Travis: We voted to change it.

Wanda: The Family Support Council has already voted for Family Support 360

Coordinators. We would just like to have more consensus around it.

Dawn: What agency suggested?

Wanda: ADD. They support us federally.

Mike: Made a motion to change name to Family Support 360.

Anne: Second the motion.

Patrice: From my prespective, it's not so much the name that matter it is the person attached to that name.

Travis: You have a point but we make a big deal about People First Language, not because it would change who I am, it would change perspective of who I am.

Shirley: Is it essential that they have the same name? Couldn't they be Family Support 360 and Personal Support 360?

Travis: That was the big question last time.

Brooke: We all come from the same waiver and it would just be easier and seamless if we had one name. Documents, brochures, etc.

Jean-Claire: Would it be possible to drop the family and just be Support 360.

Travis: I liked the name from Shirley: Personal Support.

Anne: Can we call the question?

Travis: Those in favor of changing the name to Family Support 360 say aye. Motion passed.

# Next meeting dates:

Sept 19<sup>th</sup> in Sioux Falls at Sioux Vocational Services. The PLANS group will meet on the 19<sup>th</sup> and the Core Stakeholder group will meet on the morning of September 20<sup>th</sup>.

Meeting adjorned.

